

BEHAVIOURAL RESEARCH PRIORITIES: Developing Effective Strategies for the Prevention of HIV in India

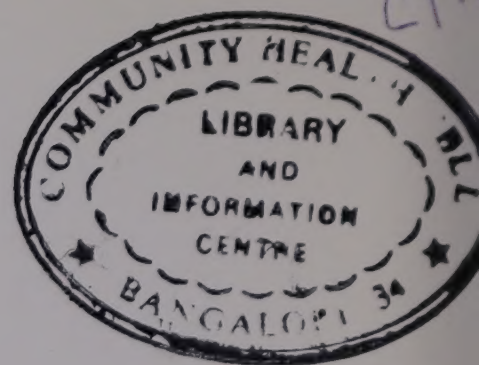


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Indo-US Workshop on
Behavioural Research Priorities:
Developing Effective Strategies for the
Prevention of HIV in India
April 24-28, 1995

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Cell for AIDS Research Action and Training (TISS)
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The Indo-US Workshop on
**BEHAVIOURAL RESEARCH PRIORITIES: DEVELOPING EFFECTIVE
STRATEGIES FOR THE PREVENTION OF HIV IN INDIA**
April 24-28, 1995

A REPORT

CELL FOR AIDS RESEARCH ACTION AND TRAINING
Department of Medical and Psychiatric Social Work
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The Cell for AIDS Research Action and Training (CARAT) was established in April 1993 under the sponsorship of the Ford Foundation, New Delhi Office, India. Its objectives are to undertake training and research, initiate action projects, provide consultancy and collaborate with government and non-government organisations (national as well as international) in the fields of STD, HIV, AIDS and reproductive health.

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EXECUTIVE SUMMARY

- I. The "Indo-U.S. Workshop on Behavioural Research Priorities: Developing Effective Strategies for the Prevention of HIV in India" was held in Bombay at the Tata Institute of Social Sciences (TISS) from April 24-28, 1995. It was organised by the Cell for AIDS Research Action and Training (CART) in collaboration with the World Health Organization, the National Aids Control Organization, the National Aids Research Institute, the U.S. Public Health Service, the Johns Hopkins University School of Medicine and Public Health and the Embassy of the United States, New Delhi. The approximately 60 participants included governmental and non-governmental representatives, behavioural researchers and research administrators from both countries, senior policy officials of WHO and other international experts, and representatives of bi-lateral and multilateral funding agencies.
- II. During the workshop the participants:
 - Reviewed the global and Indian status of the AIDS epidemic and behavioural research related to it.
 - Discussed the state of knowledge about sexual and other risk behaviour in India.
 - Identified areas in need of behavioural research in order to develop effective HIV prevention strategies.
 - Heard field reports from researchers and field workers involved with women, truck drivers, injecting drug users and youth in India.
 - Clarified that good behavioural research is underway in India and discussed what additional research would be useful.
 - Reviewed the principles of behavioural and intervention research design.
 - Discussed corollary issues such as funding, ethics, and political advocacy in the context of behavioural research.
- III. Following their discussions the participants met in working groups which integrated researchers and service providers, thereby demonstrating that in the HIV prevention area, these divisions of responsibility are often artificial and that by working in tandem very good results can be achieved. The working groups successfully developed research-oriented plans of action to:

- Promote safer sexual behaviour in adults.
- Promote safer sexual behaviour in youth and adolescents.
- Promote safer drug use.
- Improve AIDS related health services including blood supply.
- Improve reproductive health services including STD prevention and treatment.
- Strengthen behavioural research capacity.
- Strengthen HIV/AIDS care and support services.

IV. The results of the meeting included the development of recommendations for the government, international organizations, funding agencies, and individual researchers. The workshop also allowed participants an opportunity to begin preparation of several new Indo-U.S. behavioural research proposals. Overall, the workshop helped clarify the value of behavioural and intervention research to support AIDS prevention and control activities of non-government organisations.

The recommendations and conclusions which resulted from the workshop deliberations included:

1. Giving highest priority to behavioural research to understand the likely progression of the AIDS epidemic in India and to guide the development and testing of AIDS prevention strategies.
2. The National AIDS Control Office (NACO) should establish a special expert committee (perhaps through the Indian Council of Medical Research [ICMR]) to encourage the expansion of behavioural research and to evaluate and approve behavioural research proposals. Research partnerships involving NGOs and trained behavioural researchers should be given priority for receiving financial support and publishing their research findings. To assure proper proposal review and support for this critical area of research, experts who understand behavioural research and intervention development must be involved in the review. A committee of such experts could also serve as advocates for the expansion of behavioural research activities in India.
3. Behavioural research related to the AIDS epidemic is politically charged and technically difficult. Investigators involved in behavioural research and intervention development must always be aware of the potential impact of their efforts on society and on individuals. Researchers also must recognize that sexuality research addresses the most complex area of human behaviour and that there are many technical, ethical and social challenges in this research which must be considered.
4. What is most needed in India is behavioural research directly linked to the development, refinement, testing, and evaluation of interventions which prevent the spread of HIV. Research should not be limited only to descriptive studies of

risk behaviour although such studies are often the necessary first steps in "action oriented" research. Reliable behavioural data is urgently needed for patient advocacy, policy development, program planning and public communications.

5. Any barriers limiting collaboration between "NGO Activists" and "Researchers" need to be overcome. This can be done by devising optimal strategies to prevent AIDS. This will result in the linking of the research and program development skills of trained behavioural scientists with the insights, motivation and practicality of NGO activists involved. Such linkages will be multidisciplinary and will require concerted effort and goodwill.
6. Effective HIV prevention and control research requires creativity. While the highest scientific standards must be maintained to assure that research findings are reliable and reproducible, existing paradigms must be questioned and expanded. The types of research methodologies used must extend beyond randomized control trials to include more flexible methods. Both quantitative and qualitative research must be integrated to achieve real insight into behaviour and with a high level of confidence in any research findings.
7. Behavioural research objectives must be realistic, achievable and clearly defined. In HIV prevention research it is important to seek understanding of behaviour and behavioural change which is directly relevant to risk behaviours. NGOs have special practical insights in this area.
8. Research results must be published and disseminated. Organizations like the ICMR, NACO and others involved in AIDS research should assure that the data collected from NGOs and others involved in behaviour research and intervention development and testing is disseminated.
9. Those involved in intervention development and service delivery must contribute to the development of the behavioural research agenda and HIV control policy in India. Research priorities should be developed based on the experiences of those involved in trying to effect behavioural change. This is necessary so that research findings are immediately relevant to prevention activities, so that research priorities reflect the social realities of target populations and also environmental limitations which restrict behavioural change, are known to researchers. It is essential to convey research priority advice from the grass-roots to the policy makers and academic researchers.
10. Those involved in behavioural research and intervention development must be aggressively involved in publicly confronting social and political constraints which limit behavioural research in India. As research on HIV transmission risk behaviours address highly sensitive areas of Indian society, behavioural researchers (in NGOs and other organizations) must be more aggressively involved in public advocacy than are researchers in less controversial areas of health

research. The researchers must specifically address religious, political, gender and class constraints which limit research essential to control HIV transmission.

- V. In the closing remarks, the participants involved in NGO-based HIV control activities noted that the restrictions imposed by scientific research methodologies are worth the trouble when they are used pragmatically in real-life intervention development and testing. When partnerships are developed involving interventionists and researchers, several expectations must be met to maintain trust, cooperation and mutual benefit: research findings must be made widely available in a readily usable form; the human subjects of the research must receive improved services as a result of their involvement; and ethical issues of confidentiality and publication credit must be properly addressed.

In the concluding session of the workshop, Dr. Qureshi emphasized the importance of social marketing as a tool to change risk behaviour and to introduce prevention measures. He encouraged participants to immediately launch research activities and not to get delayed by bureaucratic difficulties. He also suggested that research be conducted on some issues like the "Economic impact of AIDS" and "Sex education". He advocated for increased collaboration with experienced U.S. researchers; expansion of media use; the development of more opportunities like the workshop to discuss research methods and to share materials and information; and the need to expand community organizations into research organizations.

The meeting concluded with commitments to continue the dialogue initiated at the workshop and to communicate the conclusions to government officials and funding bodies.

INTRODUCTION

The AIDS epidemic is causing concern to health practitioners, policy makers, academicians, researchers and politicians the world over. Developing countries, especially, are expected to bear the brunt of the surging phenomenon which threatens to affect millions. With no likelihood of any cure in the near future, the AIDS crisis has deepened and has compelled all concerned to look for probable solutions to stem the same within the existing frameworks of prevention and research. According to the Institute of Economic Growth (IEG), New Delhi, the number of Indians presently suffering from AIDS is estimated to be as high as 10,000 with 1.2 million already affected with HIV with the numbers expected to grow in alarming proportions.

Given the present circumstances, the only way to delay or prevent the spread of HIV is through effective risk reduction and behaviour modification strategies. Underlying these strategies is an urgent need to understand risk behaviour and the determinants of behaviour change.

Subsequent to the formation of NACO and the interest of funding bodies, behavioural research has no doubt received attention but it is yet to be given top priority by researchers and field practitioners alike. In November 1993, a national workshop on Sexual Aspects of AIDS/STD Prevention in India was organised by TISS. The participants agreed that behavioural research in the country was still at its nascent stage with focus on high risk groups and use of quantitative methods which did not give sufficient insights into human sexuality and its implications for sexually transmitted diseases and reproductive health. There was need to use innovative research approaches complementing the Knowledge, Attitude, Practical and Behaviour (KARP) studies which characterized the initial period of the epidemic.

The present workshop on behavioural research priorities was a consequence of the ideas generated in the 1993 workshop. The objectives of the present workshop were:

- i) To review the "state of the art" in behavioural research related to AIDS control.
- ii) To identify areas for priority research.
- iii) To initiate ongoing dialogue and research co-operation.
- iv) To prepare a plan of action for developing collaborative research programmes.

The workshop was convened by CARAT with financial support from NACO; WHO/GPA; Public Services Group and Johns Hopkins School of Public Health, USA; and the Embassy of the United States, New Delhi. Workshop participants represented national and international organizations, from both government and voluntary sectors and from academic institutions and donor agencies.

Following the welcome by Prof. Vimla Nadkarni and the lighting of the lamp by Mr. Gray Handley, Dr. M. Watsa and Dr. Van Dam, presentations and commentaries were made by experts and representatives of various organizations. Papers on the "state of the art" of behavioural research for planning interventions and specific research approaches were presented. This was followed by presentations on quantitative and qualitative approaches which helped the working groups to evolve their respective action plans.

In the closing remarks, participants involved in NGO-based HIV control activities noted that before the workshop, the interventionists felt the existence of a division between "white collar" academic researchers and "blue collar" NGO interventionists. The workshop made it clear that both "camps" can and must work together to increase program effectiveness and that in these collaborative partnerships, each "side" is essential to the activities of the other. All participants reiterated that the restrictions imposed by scientific research methodologies were worth the trouble when they were used pragmatically in real-life intervention development and testing. Interventions can be reliably improved with systematic documentation and evaluation.

The participants were urged to consider:

- the economic impact of AIDS and the need to address it in interventions;
- what should be included in sex education curricula and who these should address;
- research on the value and impact of sex education;
- increased collaboration with experienced U. S. researchers;
- expansion of media use, especially "folk media" to health messages;
- the development of more opportunities like the workshop to discuss research methods and to share materials and information; and
- the need to expand community organizations into research organizations.

The meeting concluded with commitments to continue the dialogue initiated at the workshop and to communicate the conclusions to government officials and funding bodies. TISS was congratulated for convening a productive, educational and inspirational workshop. Much work remains to be done but it is clear that the commitment to confront the HIV/AIDS epidemic is present in India.

THE CONTEXT

Epidemiologically, the majority of cases of HIV infection in India could be attributed to heterosexual contact and intravenous drug use with prevention the only remedy. However, there were many barriers to implementing preventive measures in the face of incurability, guilt, fear, and ostracism.

Behavioural research can provide pointers for intervention which need due attention. Organizations in India and in the United States as well as international bodies were thinking along the same lines. In this context, it was essential to share knowledge and collaborate to broaden the concern all over the world and illuminate research undertaken in the developed world.

NACO's participation was the key to ensure research collaboration as the underlying effort in the workshop was to launch and revive research through collaborations in order to understand the progression of the AIDS epidemic and their use for effective advocacy and interventions.

Review of behavioural research methods and challenges related to global prevention of HIV/AIDS

Tracing the history of social and behavioural research in the last 12 years was essential as the studies would provide guidelines for interventions and identify critical lacunas in research provisions whether technical, conceptual or political. Research priorities for AIDS had been influenced strongly by "political considerations" and consequently, the availability of funds depended on that. Governments all over the world were reluctant to face up to the issues raised by the epidemic, be it homosexual or heterosexual behaviour or injecting drug use that facilitated HIV transmission.

The three phases of social research covered:

- i) Risk behaviour and their determinants in the first 7-8 years of the AIDS epidemic.
- ii) Cultural meanings and responses in recent times.
- iii) Economic and social impact, HIV related inequalities.

The studies in the first phase were population surveys focussed largely on identification of risk behaviour and their determinants, unsafe sexual practices and/or unsafe drug

* Presenters: Peter Aggleton and Kevin O' Reilly

use. They were supported by WHO/GPA and National AIDS Program. The outcomes of these studies were varied. While they provided an insight into the diversity of human sexual behaviour and drug related behaviour, they also identified factors predictive of risk related behaviour with a given population. On the other hand, politically unsavory findings of the researches were largely ignored with little or no effort forthcoming to reduce incidence of HIV. The findings also received scant attention from health practitioners who resorted to preaching abstinence and fidelity to populations where they were not relevant. Therefore, the challenges in this period were variations in meanings, problems of quantification and appropriate explanatory frameworks.

In the second phase of research, sociological and anthropological analysis came to the fore with focus on the cultural systems within which behaviour becomes meaningful — on motivations of people towards sex and drug use, subcultural norms, peer expectations and beliefs as well as social attitudes. This was necessary to develop effective interventions. The research in the second phase therefore focused on studies of people's understanding of what HIV and AIDS meant, and studies of sexual and drug-related meanings, cultures and identities. The challenges for the second phase were origins of beliefs, popular perceptions and cultures; power and its role in structuring meanings and beliefs; and limits to sexual negotiation.

The third phase of research, which is an on-going one, takes into account the vulnerability of certain specific populations to the infection and reasons for the same; accessibility and power issues focussing on quantification and prediction of impact and response; determinants of positive and negative responses, including discrimination, stigmatization and denial; and forms and determinants of HIV-related inequalities. The challenges in the third phase included quantifying impact at household and community levels and relating impact to responses; alleviating HIV-related discrimination, stigmatization and denial; maintaining a high profile for HIV related intervention; and the political economy of risk.

Interventions had received very little attention as seen in the majority of articles published on sexual behaviour and AIDS/STD prevention. An example of empowerment of women vis-a-vis targeted interventions is cited here:

In Thailand, interventions were focussed on commercial sex workers in such a manner that brothel owners and police were convinced and accorded the responsibility to enforce condom use. While the woman herself was relieved of the burden of negotiations, the incidence of STD dramatically declined from 13 to 1.5 percent.

Another instance of empowering women was in Zambia where they lived in the city but travelled to the fishing sites to procure fish from men and then sold them in the city. Gradually, it was a phenomenon of more women to buy than men to sell fish. Consequently, the men began to sell fish to women who would pay and also indulge in sexual activity. Formation of a co-operative of these women was the only way to stop the exploitation.

While collaborative efforts were very good as had been evident in the past in heart disease and cancer prevention, the actual resultant percentages were low. Inevitably, the expectations in the case of the AIDS epidemic was very high. There was a lack of evidence of “actual” interventions and need for studies on the same especially in India. It was necessary to obtain comprehensive and exhaustive information about the local situation before launching interventions in terms of nature and size of the problem: behaviours involved; determinants of behaviours and barriers and facilitators of change. A study on the modes of transmission, specific groups who practice the behaviours, the specific circumstances; the location; and the frequency of the behaviour would go a long way in determining the nature and size of the problem.

The *determinants of behaviour* can be classified into two distinct categories:

- a) From *theories* of behaviour which include perception of risk, perception of self-efficacy, perception of social norms and perceived desirable outcome of behaviour change.
- b) *Barriers and facilitators* of risk or change which include key questions of “control” and existing channels of communication.

Although the theories of behaviour were useful for HIV/AIDS prevention, they were inadequate for intervention. The theories were clearly western in origin and were “rational” in their explanations while most human behaviour was irrational. The prime “actor” in sexual behaviours needed to be acknowledged and both parties involved were unequal as in the case of man-woman relationship.

The challenges, thus, envisaged were:

- How to gather this essential information?
- How to turn this information into intervention?

The situation called for loads of patience from funders, researchers and practitioners alike to emerge with learning from experience.

There was indeed a change in attitude towards research, particularly pre-intervention research which inevitably proves invaluable for planning subsequent interventions. It was important for NGOs to document their processes of intervention which was a major gap. There was also the need to develop a rapid assessment method with an inbuilt assessment plan with a clear time frame so that interventions could be better planned with emphasis on one learning a great deal from secondary data.

The HIV/AIDS epidemic and patterns of risk behaviour in India - Epidemiological features of the transmission of HIV and other STDs

Surveillance activities began in India in 1986 with the primary objective being advocacy. ICMR initiated the first task force in 1985. The first HIV positive case was reported from Madras in May 1986, and the first AIDS case from Bombay in October 1986. Prevalence of HIV in intravenous drug users was first seen in Manipur in 1990. As the epidemic spread, more facilities for detection were set up and by 1995, every state and union territory had reported HIV/AIDS Cases. Sixty-two surveillance centres have been set up all over the country.

Among commercial sex workers in Bombay, the epidemic progressed rapidly with 42 percent seroprevalence in 1993 to over 50 percent in 1995, with Goa following suit and Calcutta with a slower rate of increase. Among STD clients in Vishakapatnam, 10 percent were HIV positive with 1 percent seroprevalence among blood donors. Till date (April 1995), approximately 1100 cases of AIDS in India were reported with Maharashtra and Tamil Nadu housing the highest number of patients. Seventy eight percent of the infection was through heterosexual contact. From the given scenario, it was possible to conclude that:

- There is an overall increasing trend of HIV/AIDS in India.
- Distribution of the problem is highly varied in different parts of the country.
- In certain areas, there is a perceptible percolation of the problem to the general populations from the core groups.
- The problem affects people in sexually active and economically productive age groups.
- There was an urgent need for intensifying efforts with support from all sections.

As far as STD was concerned, 372 STD clinics were set up all over the country but only 30 percent were found to be active. Also, ante-natal clinics regularly checked for STD and the government had also initiated specific population based studies.

The sentinel surveillance for HIV infection included unlinked anonymous screenings at regular intervals of high risk populations like STD clinic attenders, injecting drug users and low risk populations like ante-natal clinic attenders. HIV trends among STD clinic attenders according to two rounds of sentinel surveillance reports showed the following:

Place	1st Round	2nd Round
Bombay	23.00%	36.00%
Visakhapatnam	2.30%	7.80%
Madurai	6.40%	6.50%
Madras	2.70%	3.80%
Ahmedabad	7.00%	6.00%

Overview of research on sexual and other risk-related behaviour and interventions in India

Analysis of Trends

The presentation was based on available research papers, reports, news bulletins, journals, abstracts, newspaper clippings and analysed trends in behavioural research. Specific target groups and analysis of trends were distinctly categorized as follows:

TARGET GROUPS	ANALYSIS OF TRENDS
1. Youth and adolescents	1. Areas of research
2. Women	2. Research Design
3. Female sex workers	3. Tools of Data Collection
4. Men	4. Methods of Analysis
5. Men who have sex with men	5. Strengths of the studies
6. Blood donors	6. Problems, constraints and gaps
7. Truck drivers	
8. Eunuchs	
9. Injecting Drug Users (IDUs)	
10. STD patients	
11. Street children	
12. Health workers	

Research with college students and adolescents focussed on sex education, information, AIDS awareness, pre-marital sex, misconceptions, sexual abuse, sexual negotiations, contraception and abortion, development of doctors and teachers as resource persons, aspirations, peer pressure, work styles and hygiene.

With women, issues ranged from health education, contraception, knowledge about reproductive health, health-seeking behaviour and beliefs, to sexual negotiations, practices and attitudes, etc. Attempts have been made to understand the issues which concern female sex workers like reasons for sex work, number of partners, knowledge about HIV/AIDS, safe sex practices, use of condoms and constraints in using them, power structures, *devadasi* system and so on.

Research with blue collar migrant men, loom workers, male jail inmates, clients of sex workers focussed on pre-marital sexual behaviour; number of partners in extra-marital sex; anal, animal and group sex; experience of homosexuality, addictions, awareness of STDs and AIDS and condom use. Male sex workers, bar boys, rickshaw pullers, taxi drivers, masseurs, bisexual men, gay men and eunuchs (*hijras*) were the target groups for researches on men who have sex with men. Issues ranging from types of sexual behaviour, cultural taboos and impact, use of condom to knowledge of AIDS and risk behaviour were also researched upon.

Blood donors were interviewed on aspects of frequency of donation, reasons for selling blood, use of condoms, knowledge of infections and use of testing and counselling facilities. Truck drivers were interviewed on reasons for visits to sex workers,

sex-settings, sex seeking behaviour, attitude towards STDs, HIV/AIDS and use of condoms. Areas of research with IDUs in North-Eastern states, Tamil Nadu and Maharashtra were types of drugs/techniques used, reasons for drug use, frequency of use/costs, sources of supply, needle sharing practices, knowledge and attitudes towards HIV/AIDS and STDs, sexual behaviour and use of condoms, changing patterns of drug use and prevalence and reasons.

STD patients were also interviewed on aspects of knowledge and attitudes towards HIV/AIDS, risk behaviour and health seeking patterns, factors leading to non-compliance and condom use. Health workers' attitudes, knowledge, practices and beliefs were examined with respect to HIV/AIDS. In the context of street children, issues ranging from work patterns, living conditions, problems, survival behaviours, access to health services, prevalence of STDs and drug abuse, sexual behaviour and patterns to the needs of girl children were tackled.

The above researches were conducted mainly through surveys, case-studies, intervention studies, participatory or action research by administering anonymous self-administered questionnaires, focus group discussions, in-depth individual interviews, key informant interviews and participant observations.

While the studies were of value, some of the gaps revealed lack of documentation, training, funds, methodological weaknesses, inappropriate selection of research design, and generalisations from small samples. The researches had helped in understanding behaviour, changing trends, areas for further research, planning interventions, social processes and also establishing base-line data and procuring in-depth information.

Specifics related to sexual behaviour research

Research in this sphere was fairly limited in quality and quantity. Stereotyping and myths surrounding the issue were far removed from the actual patterns of sexual behaviour. With reference to pre-marital sex, although the phenomenon was not as common in India as in the United States, it was also definitely not as rare as is often made out to be. Information on partners for pre-marital sex was inadequate although neighbours, relatives, female sex workers, friends, students and fiancée have been mentioned in a few studies. While there have been studies to indicate that this practice was institutionally permitted in tribals, there was no evidence of the same in recent times. Pre-marital sex has also been found to be high among STD patients as indicated in the studies of Savara and Sridhar (1994) and Narayan (1984).

Data on extra-marital sex were also limited. Due to social conditioning, men were more promiscuous than women. For example, Basu's study in Calcutta, Delhi and Madras found that the phenomenon was 9 percent among men and less than 3 percent among women.

The number of FSWs in India is difficult to estimate because of the wide varieties and geographical distribution of FSWs. They lead a life of exploitation by pimps, landlords,

“madams”, financiers and policemen. They have little or no access to good health facilities and frequently suffer from STDs. Quite a few of them are deserted women who support their families back home. According to Jana *et al* (1994), in many successful interventions with FSWs by NGOs and government agencies, trained FSWs were used as peer group educators.

There was little data on the “devadasi” system and the category of FSWs known as “call girls”. Even though the sex industry is so rampant, very little data was available on the clients of FSWs, their socio-economic characteristics, ways of life and sexual preferences. Some of the groups identified were truck drivers; workers in transport and manufacturing firms, living away from home for a long length of time; visitors to fairs and festivals; and students, who formed part of the clientele.

Men having sex with men was yet another group in which there was complete darkness about prevalence, estimates, etc. A survey of 1200 self-identified homosexual men of South Asian origin mostly in India by Khan (1994) revealed that majority of them were married and their first homosexual experience had been with uncles or cousins.

Eunuchs have been subjects of study for anthropologists, but there has been little focus on their sexual practices. However, it is known that eunuchs do engage in sexual activities with men for money and are often passive partners in anal intercourse without condoms, thus making them highly vulnerable to HIV and other STDs.

Male sex workers often live in red light areas of metropolitan cities. Helpers of truck drivers, homeless young men and poor boys are forced to provide sexual services to retain their jobs.

With regard to the usage/non-usage of condoms in the Indian context, condoms have always been associated with family planning. And family planning is seen to be the responsibility of the woman, thereby, leading to resistance to the use of condoms. Also, as far as FSWs are concerned, the issue of their powerlessness in the face of the clients’ unwillingness to use the condom throws up many problems. Some NGOs have demonstrated that planned interventions and educative programmes can increase the use of condoms significantly among truck drivers.

Out of a total of 17,124 HIV positive cases in India (upto 1994 December), 2942 (17.20 percent) cases were reported from Manipur, Nagaland and Mizoram. The presence of the high rate of HIV was inevitable because of sharing unsterilized equipment while injecting drugs. They were distributed mainly in urban, peri-urban and areas around the national highway route No. 34 of Manipur and Nagaland due to the easy availability of relatively cheap heroin. In addition to sharing of injection equipment, there was a high frequency of unsafe sexual contact. Findings of surveys indicated a fair knowledge of acquiring HIV/AIDS among them.

Highlights of the 65-city study on High Risk Behaviour in India

The primary objective of this study is fact-finding for advocacy and planning. The other objectives include information for intervention, identification of client groups and focus on areas for further research. The high risk behaviour groups included in the study are female sex workers, men having sex with men, eunuchs, injecting drug users, frequently travelling males and slum populations. The cities chosen have a population of over 5000 people.

The expected outcomes are maps of locations of high risk behaviour; estimations of number of persons at each location; descriptions of patterns of behaviour; locations and activities; of contacts and links; identification of networks within which the behaviour occurs and obstacles for interventions; and identification of NGOs, groups, agencies working or who could work with such groups.

A variety of organizations were involved at each site of the research. The main participating centres were city colleges and persons involved were oriented to the study and trained in the various aspects. The data showed that every city is different in the locations of the brothels and spread, and in the phenomena of "day", "night" and "casual" sex workers.

Some of the obstacles in data collection were the innumerable misconceptions about HIV/AIDS, perception of oral sex as "dirty", low priority accorded to health care and difficulty in accessing private practitioners and intercity mobility. The study also found that knowledge of STDs among high risk behaviour groups was fairly high as many of them did take regular preventive measures for STDs and had a deep faith in healers. Other commonalities found especially among FSWs of different cities were that they had no support systems whatsoever; they faced police harassment and lived in abysmal conditions. It was clearly apparent that the health care delivery system was not appropriate at all.

The broad outcomes of the experiment were:

- The possibility of fruitful collaborations;
- Evidence that research experience creates momentum for action;
- Perceptible change in perspectives and motivation of involved personnel;
- Involvement of varied agencies in attacking the issue;
- Beginnings of interventions in some cities;
- Clear indication of a need for a broader perspective in issues like police harassment, health services, apparent double standards and understanding of women's issues specifically in the context of AIDS.

With the existing methodology, it was not possible however to access men who had sex with men and injecting drug users. Sexual activity which took place outside of the circuit of female sex workers needed to be looked into. Future areas needing research was the role of alcohol use among high risk behaviour groups; relation of type of city,

occupation, demographic patterns with high risk behaviour; and links between rural and urban high risk behaviour.

Field reports from practitioners involved in HIV/AIDS intervention programmes

Focus on Women

It is a centuries old practice to view women's health in the narrow realm of reproductive health while all other aspects are ignored. This influenced the design and the delivery of health services. This particular report focusses on women's health problems as observed in a large public hospital where the regular interventions included counselling, material assistance, referrals, networking and advocacy. Some of the common issues were identified as abortion and rape, anaemia, adoption, motherhood, HIV/STD infection and occupational risks of working in a health care setting. These implicated on the physical and mental health of the women and increased their vulnerability to HIV/AIDS and STDs.

The multitude of factors which increased high risk behaviour among teenage girls and women can be understood in the context of their socio-cultural beliefs, life circumstances, poverty situations, etc. Deep rooted patriarchal beliefs perpetuate the "culture of silence" in the face of incest, rape, sexual abuse, fraudulence, desertion, repeated exploitation and women's powerlessness to fight back. Although the maternal health figures in Maharashtra seemed optimistic, teenage pregnancies were rampant and abortion clinics were mushrooming all over the countryside. Sixty percent of the women who reported to the hospitals for medical termination of pregnancy were under 16 years and unmarried. Many of them did not even know that their behaviour was risky.

Gender discrimination and violence against women heightens vulnerability. Post-abortion complications like repeated miscarriages, secondary sterility, etc. lead to acute anaemia requiring frequent blood transfusion increasing the risk to HIV infection. Sixty percent of blood transfusions in India were to treat cases of acute anaemia.

The other hazard is related to breast-feeding. A woman who has undergone a caesarean is usually discouraged from breast-feeding her baby which is breast-fed by other nursing mothers whose HIV status is unknown. Women are also at risk because of their total lack of control on sexual practices. In addition, they are burdened with the responsibility of nursing, hospitalisation and economically supporting the husband and the family. More often than not, women are deserted with children as a consequence of the stigma attached to AIDS.

Focus on Truck drivers

This presentation was based on the interventions with truck drivers at Uluberia Resource Centre in Howrah district of West Bengal, about 55 kms. from Calcutta, by

* Presenters: Vineeta Chitale, Kiran Verma, Eldred Trellis and Suniti Solomon.

the Bhoruka Research Centre for Haematology and Blood Transfusion. The Uluberia site made it possible to undertake in-depth interventions owing to the stops made by some truck-drivers (800 to 1000 trucks passed through everyday). This aided in effectively imparting messages on sexual health.

Prior to direct interventions, the organizers conducted a pre-intervention research in three phases over sixteen weeks on a total sample of 300 truckers and their helpers (100 using the qualitative approach and 200 the quantitative). The survey covered data about their socio-economic status, sexual behaviour pattern, knowledge and magnitude of STDs, condom knowledge and usage, and self-perceptions. In-depth qualitative insights were explored into sexual behaviour. The point prevalence study on the magnitude of STD/HIV among the target group and to monitor the future trend of the disease identified 7.40 percent seropositivity in the blood samples.

The findings necessitated full-scale intervention which was then launched with the appointment of specially trained medical officers and social workers. The activities covered information on HIV/AIDS/STDs, importance of prompt treatment and management of STDs, motivation for blood testing for STDs and HIV, pre- and post-test counselling, promotion and free distribution of condoms, etc.

Evaluation of the intervention undertaken through two studies in 1994 — on condom knowledge and usage and point prevalence — reflected that 90 percent of the truckers knew about the protective function of condom; only 7.1 percent were regular users, 30 percent were irregular users and 60 percent still did not use condoms. HIV seropositivity had reduced to 5.2 percent as against 7.4 percent in 1993. Due to the poor quality of condoms supplied by the government, there was a plan to install condom vending machines with superior quality condoms.

The broad future plans for the Uluberia Centre included: creation of more nodal centres; acquiring greater understanding of the sexually active network to track HIV; identify the particular community and to conduct an HIV and cohort study; to upgrade skills of workers; training and networking with other NGOs. The experiment was replicated at Ichchapuram and Bangalore. In a similar experiment in Sub-Saharan Africa, the intervention was coupled with interventions with female sex workers.

Focus on Injecting Drug Users (IDUs)

This presentation is based on interventions with IDUs in Manipur. With a population of 1.83 million, Manipur has more than 30 different tribes. In September 1994, out of 3,091 seropositive blood samples (from a total of 31,481 blood samples screened), 78 percent were due to injecting drug use.

The current services and interventions available for IDUs were de-addiction and rehabilitation facilities, outreach programmes, and jail and street level interventions. The 18 centres for deaddiction and rehabilitation in Imphal and Churachanpur focus on a step programme of Narcotics Anonymous, prevention and family life education. Outreach programmes comprise awareness activities about safe injecting practices,

use of condoms, motivation of community-based youth clubs and women's groups for care of AIDS patients.

As the stigma attached to the disease was very high, it was not easy to initiate self-help groups. In several instances, infected people had gone underground due to violent treatment and threats. There was resistance to promoting condom use as it was viewed as "encouraging immoral" behaviour and was as yet to be associated with protective functions. Most tribes were Christian and influenced by the Church which opposed condom use.

Some of the problems encountered in outreach programmes include resistance from IDUs because of stigma from drug use, inaccessible sexual partners, advocacy with different political groups, difficulty in availability of liquid bleach and condoms and young widows turning to commercial sex.

Jail and street level interventions were mainly carried out by an NGO called SASO. The Sajiwa Jail, exclusively for IDUs (the parents believed their children would be cured by forced abstinence), has a special ward for HIV positive persons who were constantly ill but had no medication. Rigorous follow-up had to be done with families for better care. Street level interventions were basically done by former IDUs because of their extensive contacts. There were no studies, only verbal reports stating injecting drug use was prevalent in jails and the rate of infection was high. Uncooperative jail authorities prevented meaningful interventions.

Focus on Youth

Y.R. Gaitonde Centre for AIDS Research and Education worked with schools, colleges and youth in informal settings through sexuality workshops. It was an uphill struggle for the organization to convince school and college principals to initiate the programme on sexuality, generally arranged for one or two days coupled with a three-days' peer educators training. For illiterate youth, a 3 to 5 days' programme using various art forms was conducted. Several popular myths and misconceptions were documented. The art form programmes were conducted mainly through resource persons in the fields of drama, painting, sculpture, street plays, puppetry and other forms of folk art.

The main objectives of the module were to impart information, motivate students for action, clarify myths and misconceptions, foster positive attitudes about HIV related issues and living with HIV infection. The constraints were: denial of AIDS problem in India; resistance to sex education and use of visuals; fear that the education and condom messages will make children promiscuous; embarrassment to deal with mixed groups; and shyness and embarrassment of teachers to carry on the messages. With time, the programme has gained lot of popularity among youth who were fairly active in peer education. Documentation and lack of staff were some problems faced along with the dilemma of whether abstinence needs to be advocated or not during the programme.

Behavioural/Intervention research design methodologies: Field reports from other behavioural research experiences

Focus on Women

Detailed methodologies and the process involved in two studies conducted in Indonesia were presented.

The first study was conducted with commercial sex workers (CSWs) from the largest brothel near the Indonesian harbour. The entry interviews of 63 CSWs were conducted by 12 psychologists and an anthropologist during a three week period which revealed the demographic characteristics of the respondents and their clients.

Focus group discussions were used extensively, with each group being exposed to nine sessions which focussed on different issues like attitudes towards sexuality, facts about reproductive organs, contraception, STDs and AIDS. Information was also given on the female condom along with practical demonstration. CSWs were also trained in communication and negotiation techniques related to "safer sex" through discussion and role play. Peer group discussions and sharing of experiences helped a great deal. Subsequently, exit interviews were also conducted. The outcomes of the interventions were documented in areas of gender relations and sexual negotiations.

The exit interviews revealed positive results like using the condom except with their "boyfriends" and "regular customers"; more confidence in dealing with their customers in persuading them to use condom or using the female condom themselves. The study revealed that it was not enough to empower women for only AIDS prevention; the issue needed to be more broad-based. There was a need to research on how women perceive sexual negotiations; to undertake collaborative studies; evaluation and dissemination; and to focus on ethical issues.

The objectives of the second study were to ascertain knowledge of HIV/AIDS, its transmission and prevention, constraining and enabling factors/myths that inhibit/encourage women to talk about HIV/AIDS and related issues to their partners, disseminate information during group discussions and through leaflets/brochures, and through other NGOs to women.

At the outset of the study, a day's seminar on AIDS was conducted to touch upon issues of knowledge, discussion of sex issues, approaches/strategies to overcome barriers, etc. During the group sessions, different issues relating to difficulties in discussing "unsafe sex" with husband/partner and strategies to overcome them were discussed.

It was observed that the Indonesian experience could probably be extrapolated to India and other countries. While there was a lot of similarity between the Indonesian and Indian cultures because of which the tools could be easily used, evaluation had not been done. As yet, no empowerment scales existed in the world.

* Presenters: Bernadette Setiadi, Michael Sweat and Richard Needle

Sexual behaviour change in the Thai Military

This presentation focussed on the behavioural interventions for reducing HIV risk among Royal Thai Army Conscripts. The advent of HIV in Thailand was fairly recent and heterosexual transmission was rare before 1988. From June 1989, a nationwide sentinel surveillance for HIV in high risk populations was conducted.

The respondents of the Thai Conscript Intervention study were conscripted by lottery and represented the lower four-fifths of the Thai socio-economic strata. The mean age at conscription being 21 years, routine health screening including HIV testing at induction was the policy since 1989. However, the practice was to induct and retain regardless of the HIV status. The study of HIV prevalence among recent northern military conscripts in different cohorts showed high HIV prevalence stable over 3 years.

At induction itself, baseline HIV screening and risk factor surveys were completed. At six month intervals, testing and risk factor interviews were conducted. All conscripts received HIV/AIDS health education during basic training and subsequently a participatory intervention was designed and implemented in eight selected camps over a period of eight months. Concurrent and historical controls were used in the analysis and the HIV and STD incidence and behavioural risk factors were assessed and compared.

Using the army's formal command structure and informal friendships, the intervention was designed based on the principles of social influence, participation and diffusion and implemented in three phases - small group discussions, selection and training of intervention teams and prevention activities. While the intensive team-based intervention influenced the peers, the diffusion model influenced adjacent companies and enabled "spill over".

There were significant changes only in self-report behaviour in the intervention groups, but not in the HIV prevalence or incidence rates. In the self-report data, the frequency of visits to CSWs had dropped and condom use with girlfriends had gone up.

Issues that emerged from the outcome indicators were that of "validity" in self reports; the fact that prevalence never goes down without mortality; the need for very large sample sizes; and difficulty in following people to gauge incidence. On the other hand, there were other facts which had to be contended with respect to design. They included companies of interest before starting, having control groups, avoiding overlaying too many interventions and considering secular change and ways to measure. One also had to look into the aspect of constant changes that take place before completion of the research and keeping track of the many influences and interactions that occur while conducting research in dynamic epidemics. Also, people often report extreme or exotic issues or what they believe others are doing or thinking. This creates a problem of generalising qualitative findings to the population level.

Some questions for consideration were : how "rapid" should research be; complexity of design, sample size, outcome indicators in terms of prevalence, incidence and self-report, and appropriate mix of qualitative and quantitative methods.

Hard-to-reach groups

This presentation focussed on the outreach programmes of the Miami Community AIDS Research Evaluation Studies (Miami Cares). The highlight of the program was that it was successful in identifying, accessing and recruiting injecting drug use in hidden populations providing risk reduction information and materials; encouraging people to get HIV tests done and return for results; facilitating changes in risk-related behaviours; and averting HIV infections.

With the commencement of the outreach programme, indigenous outreach workers located, screened and recruited eligible participants. It was found that outreach programmes are an effective component of HIV risk reduction strategies through follow-up endeavours, educational material, counselling for modification of behaviours, persuading for treatment, etc.

An initial assessment was done after informing the participants about the general purpose of the study. The process included: pre-test counselling, urine analysis, administration of the standardized risk behaviour assessment (RBA) questionnaire, extensive pre-test counselling and blood test. Intervention was then carried out through an innovative method of a personalized risk reduction strategy, followed up with a street programme in which the outreach workers helped the subject to deal with any problems countered during personal risk reduction. The outreach workers also distribute condoms and bleach and made appropriate referrals.

A follow-up assessment is conducted at six-month intervals in standard and intervention groups for comparisons. Intensive evaluation focusses on aspects of "who", "what", "how", "why", community participation and so on. Outcomes were evaluated with respect to enrollment, drug treatment and AIDS prevention, causation of drug use, change in sharing practices, use of shooting galleries, sexual practices, seropositivity, development of drug related diseases, HIV related illness, etc.

The broad conclusion that could be drawn from the research was that interventions were effective in reducing the high risk of HIV/AIDS associated with injections and other drug using behaviours. There was need for longitudinal studies to assess effectiveness of interventions in reducing and maintaining risk reduction behaviours. (Refer to Appendix I for group discussion on researchable issues.)

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Principles for designing behaviour and intervention research^{*}

Research involves a set of observations made systematically to find an answer to a question. However, though one might search for truth, one must settle for data. Observations could be made qualitatively (small numbers, more depth) or quantitatively (large numbers, less depth).

It was necessary to examine actions at every stage of the research be it design, implementation or evaluation. Questions of whether ideas are good, practical and relevant to the community need to be asked and whether the interventions are as extensive, intensive and consistent and if so, whether the goal has been achieved. Finally the need for changing certain aspects of implementation may also be examined. The ultimate goal should always be to achieve a change in the community and should that happen intentionally, it was desirable, proving the effectiveness of the interventions.

Designing of the research project includes systematic observations and a thorough situation assessment. This starts typically with the people most proximate to the researcher and the target group; and moves on to people who are working with the target group and finally involves engaging the group in focussed group interviews and intense data collection.

Implementation involves good management of qualitative and quantitative data. Failure of effective management results in lack of baseline data, no delivery as planned, no delivery at all, and no consistency with which it was planned. Lack of consistency in thinking amongst people who conceptualized the project and the front-line also results in failure. Evaluations essentially comprise : "who" to compare, "what" to compare, and "how" to compare. While evaluations needed to be against original objectives, researchers needed to be alert to take note of unintentional outcomes. However, overly long, cumbersome questionnaires should be avoided.

It was important to use qualitative and quantitative data in a judicious way. While there were different styles of research, the demystified, participatory method was not as widely accepted. Regarding the issue of ethics about having control groups and the

^{*} Presenter: Kevin O' Reilly

aspect of deliberately “intervening” or “not intervening”, one could do it unless it was not a case of taking something away from the other community.

Methodological issues in sexual behaviour research*

The different kinds of research include formative research for diagnostic and mapping data and operations research resulting from formative research leading to drawing up of an intervention strategy and action plan. The research process comprises interaction between programme goals and objectives and research goals and objectives within the historical, social and cultural context. The role of intervention research was to influence/develop policy, intervention strategy, service delivery and communication, including advocacy.

There was a need to develop experimental studies to evolve methodologies which would require confidentiality, more active participation and less dependence on respondents or informants. Methodology for providing confidentiality and motivation was crucial. The problems encountered in doing so were the intensely private and personal nature of the issue even for “normal” sexual behaviour, “overclaim and understatement” and ethical issues. Stigma was attached to even participating in a research on HIV/AIDS.

The characteristics of “good” methodology were acceptability, reliability, robustness, stability and validity. The contentions were that there was no sacrosanct blue print methodology, “why, what and who” were starting points, adopted to socio-cultural context and meaningful in the social environment. Also, the data collection methods for different kinds of research were different. In diagnostic research, the methods included introspection, literature search, observation (participatory or non-participatory), in-depth interviews of key informants, life histories, case studies, focus group discussions (exploratory and explanatory), and diary panels. Mapping research involved methods like surveys, observation, “mystery acceptor/customer”, and diary panel. It was necessary to use creative combinations to yield composite methodologies.

Research in sexual practices would utilize focus group discussions with motivators and resisters in participation, composite methods, tested question based research, and operation research. Analysis would include description, proving a hypothesis, establishing size, projections and forecasting, establishing causalities, choosing between alternatives, evaluations against baseline/targets, setting baseline for evaluation and defining target group i.e. segmentation. It was also important to establish causality through in-depth understanding, statistical methods or through controlled experiments.

Evaluation indicators would be of characteristics which could be measurable, sensitive, reliable or valid. Indicators could be at the operational level, process level or impact level. However, attitude statements and scale require critical pre-testing.

* Presenter: Debi Basu

Qualitative methodologies

Intervention research was mainly for the purpose of local applicability. The challenge was to procure quality data about behaviour. While conceptualizing the target of the research, there were certain points to be considered:

- a) The behaviour (e.g. sexual behaviour) must be explored as complex sequences and patterns of action.
- b) Individuals have complex histories of sexual behaviour (or e.g. drug use behaviours)
- c) Need to collect data on the contexts - the social and the physical environments of the behaviours of a complex socio-economic system. For example, differences between brothels in Calcutta compared to Bombay.

The focus would mainly be on behaviours, action and events. As attitudes and perceptions when attached to behaviours have greater validity and credibility, the same procured from surveys were often of questionable validity. Also, it was necessary to be aware of certain complex patterns which include:

- The sequences and situations through which pre-teen and teen children develop their initial sexual explorations in schools, slums and other locations.
- Sequences and contexts of sexual explorations among college youth.
- Patterns of encounters in non-brothel commercial sex in streets, festivals and in tourist resorts.
- Patterns and sequences in other special groups like men who have sex with men, eunuchs and others.

Open ended key informant interviews have many uses: firstly, repeated (sequential) interviews with the same person help to develop rapport initially, follow-up to get details and lastly for internal cross-checking. Secondly, they regard the informant as an "expert" about herself, about main aspects of vocabulary, etc. in the community. They also help in getting "stories", "narrations" and "episodes" in her/his words. This method also avoids the "string of individual questions". It is also important to let the informant lead the conversation initially and subsequently interview for follow-up in more detail.

The data that in-depth interviews and focus group discussions yielded were quite different. For example, most of the young women in a Mauritian study knew about condoms, usage and disposal and enjoyed sex just as much, but few admitted knowledge of the same in focus group discussions. Some uses of focus group discussions are getting the vocabulary, "testing" an intervention idea, mapping/inventorying/listing of, for example, locations of sex workers along the highway, and getting the local community involvement (the last two signify participatory rapid appraisal methodology).

The steps of research, therefore, comprise the following:

1. Formulate questions to be answered.
2. Informant interviews in three stages which involves mapping, inventorying, listing, etc. including participatory rapid appraisal (PRA).
3. Focus group discussions along with PRA with key informants.
4. Develop quantitative methods for selected data.
5. Develop and test interventions, ideas and materials.

It is a prerequisite condition that consent be obtained especially while using unstructured methods. In the use of methods, it is essential to adopt a series of triangulations and researchers should work very closely with partners, train them and get key informants to be a part of the research team and also pay them, if possible.

Principles of designing research, ethical issues and related issues for grants and collaboration

Guide for developing prospective collaborative research programmes

These would be true research programmes of mutually beneficial collaborations with both sides having an equal stake. All publications and resource contributions would be joint as in case of equal partners.

Investigators could informally work with the other party on a proposal by drawing on the strengths of both institutions which could then be submitted to the Indian and U.S. nodal agencies and the U.S. Embassy. They would then be evaluated for technical and procedural soundness and subsequently approved and subjected to yearly evaluations prior to sanction. Budgetary provisions were flexible and depended largely on what the investigators wished to study.

It would take a minimum of 6-8 months for approval and the sanction could be for a period of 5 years, subject to annual evaluations. The proposal should be of high quality in the face of fierce competition. It was, therefore necessary for institutions to collaborate.

If an investigator submitted a proposal, the U.S. Embassy would try and find a collaborator for her/him and make available small grants for them to meet, etc. The project could be undertaken anywhere in India.

NACO's 65 city study demonstrated how collaborations could function. Political commitment, prioritization and establishing credibility and skill enhancement of organizations which were to be involved in implementation were key factors. This was ensured by organizing city meetings which included NGOs, colleges, government functionaries, community representatives and key opinion leaders to work on the data

* Panel: Saroj Pachauri, Gray Handley, Geeta Sethi and Peter Aggleton.

and plan the future course of action. Attempts were on to establish a system of accountability and reporting systems even after funding commenced.

Ideally, the objectives of social research ought to be to plan interventions and influence policy. Only certain kinds of research may be suited for collaboration and also certain institutions may have the capability to do it. There was a need to consciously keep aside impressions about governments and social research ought not to have oppositional positions to intervention programmes. It was essential that the research proposal envisage concrete interventions and initiate NGOs into research.

Collaborations were always successful when both the parties concerned were clear about how the outcomes were going to benefit each of them and expressed satisfaction that the AIDS epidemic had, in fact, bridged many a gap between researchers, practitioners and policy makers.

It was necessary to develop research priorities at the grassroots and communicate it upwards. It was necessary for NGOs not to blindly borrow ideas from abroad and develop research agenda without concentrating on developing the same with the people under local conditions.

There was need to use the outcomes of the workshop for advocacy and encourage people to engage in social behavioural research for which there was wide support. A committee should be formed to ensure accountability, with NACO in the lead, to act as a nodal body for proposed intervention, funding and research. (Refer to Appendix II for group discussions on methodologies to study various groups.)

Lessons learned*

The major lessons learned from the workshop are summarized below:

1. AIDS research was a political process and unlike any other research. There were innumerable impediments to collect information and intervene and the challenge was to surpass the framework imposed.
2. There was no doubt about the need for intervention research allowing no room for passivity but to be dynamic and go beyond standard established procedures. The emphasis ought to be on advocacy as demonstrated in the 65 city study.
3. It was essential to break down barriers by reducing the urge to compartmentalize and label, and to constantly use information to redefine activities. It was also important to learn to collaborate on areas which could yield amazing results. Coming together was incredibly productive rather than individual efforts.
4. There was a need to build capacities, infrastructure and people power, build bridges with people, groups and adopt an interdisciplinary approach to broaden outlook.
5. It was essential to be creative and go beyond psychology-based behaviour and models to think about social norms as was evident by the African experiment on

* Presenter: Isabelle De Zoysa

women who bought and sold fish. It was also crucial to go beyond assumptions of who is at risk, who is not and where interventions are necessary.

6. Consciousness and clarity about research approaches used to explode myths about evaluations, etc., was absolutely necessary as was amply evident in the study in Mauritius and also to arrive at an ideal mix of qualitative and quantitative methods.
7. It was important to be realistic about one's expectations and also accept limitations. Clarity about objectives of the research for advocacy, formative or intervention or evaluation was also necessary. In this context, it was important to learn from others and contribute to efforts in India.
8. While contributing to the development of the research agenda, it was also the responsibility of all participants to ensure that research priorities were developed at the grassroots and communicated upwards. It would be worthwhile to also examine how one could influence the political process of priority setting and project review meetings.
9. There was need to "raise hell" subverting political processes which hamper the processes of behavioural and intervention research for HIV/AIDS prevention. It was crucial to make a dent and penetrate through the layers of bureaucracy.

Recommendations

The recommendations and conclusions which resulted from the workshop deliberations included:

1. *Behavioural research, to understand the likely progression of the AIDS epidemic in India and to guide the development and testing of AIDS prevention strategies, is of highest priority.*

Since prevention of HIV transmission is the only way to control the spread of AIDS, it is essential that resources be directed toward the understanding of the determinants of risk behaviour including sexual behaviour, injecting drug use behaviour and "professional" blood donor behaviour. This understanding will facilitate the development of interventions which encourage behavioural change to reduce the risk of HIV transmission.

It was also necessary to view research in a much broader socio-economic context. Research could serve to also understand changes occurring in society. Epidemiological studies ought not to give predictions for more than 2-3 years because they do not take into account the interventions that may bring it down. There were a lot of unreported cases especially in the rural areas which needed to be taken into account. There was also the need to take into account the abundance of data available in private hospitals all over the country.

2. *The National AIDS Control Office (NACO) should establish a special expert committee (perhaps through ICMR) to encourage the expansion of behavioural research and to evaluate and approve behavioural research proposals.*

Research partnerships involving NGOs and trained behavioural researchers should be given top priority for financial support and publication.

Behavioural research proposals have methodologies and objectives which are often unappreciated or misunderstood by other biomedical and health researchers. Therefore, behavioural research proposals are often assigned a low priority for funding. To assure a proper review of the proposal and support for this critical area of research, experts who understand behavioural research and intervention development must be involved in review. A committee of such experts could also serve as advocates for the expansion of behavioural research activities in India.

This would also ensure that methodologies/techniques/tools are tailored to suit the Indian context. There was a need, for instance, to evolve rapid assessment methods to plan and get into implementation without spending so much time on planning the research. It was necessary to understand more about such methods because traditional training and stress has always been towards slow, careful planning. Researchers should also be cautious when drawing conclusions. It was important to remember that regional differences and heterogeneity were rampant among various sub-groups.

3. *Behavioural research related to the AIDS epidemic is politically charged and technically difficult.*

Such research can directly affect the lives of individuals because it focusses on risk behaviours which may invite social sanction and because the disease AIDS evokes problematic public responses. Investigators involved in behavioural research and intervention development must always be aware of the potential impact of their efforts on society and on individuals. Researchers also must recognize that sexuality research addresses the most complex area of human behaviour and that there are many technical, ethical and social challenges in this area of research which must be considered.

4. *What is most needed in India is behavioural research directly linked to the development, refinement, testing, and evaluation of interventions which prevent the spread of HIV.*

Research should not be limited to descriptive studies of risk behaviour, although such studies are often the necessary first steps in "action oriented" research. Investigators should remember that the value of their research often extends beyond the achievement of stated objectives. For example, reliable behavioural

data is urgently needed for patient advocacy, policy development, program planning and public communications.

5. *Any barriers which limit collaboration between "NGO Activists" and "Researchers" need to be overcome.*

In the field, it should be recognized that programme implementers must be and often are involved in research and researchers are often providing prevention services. A critical need is to have research findings and program evaluation data published and distributed. Optimal strategies to prevent AIDS will result from linking the research and program development skills of trained behavioural scientists with the insights, motivation and practicality of NGO activists involved with at risk populations. Such linkages will be multidisciplinary and will require concerted effort and goodwill. They also will significantly increase the overall capacity of India to respond to the epidemic.

6. *Effective HIV prevention and control research requires creativity.*

While the highest scientific standards must be maintained to assure that research findings are reliable and reproducible, existing paradigms must be questioned and expanded. For example, research might look at the social determinants of risk behaviour rather than concentrating on individual psychological models of behaviour. Also, the types of research methodologies used must extend beyond randomized control trials to include more flexible methods. It is not a question of focusing on either quantitative or qualitative research. The two must be integrated to achieve real insight into behaviour and a high level of confidence in any research finding. It was also very important to adopt participatory research methods involving the whole community.

7. *Behavioural research objectives must be clearly defined, realistic and achievable.*

Achieving a complete understanding of behaviour is usually an unobtainable goal. In HIV prevention research, it is important to seek understanding of behaviour and behavioural change which is directly relevant to risk behaviours. It is not necessary to have scientifically perfect research to gain a sufficient understanding so as to be able to plan effective programs. NGOs have special, practical insights in this area.

8. *Research results must be published and disseminated.*

Indian researchers should contribute to the global response to the HIV epidemic by assuring that research findings and experiences with interventions are made available to others in India and as well as in other countries. ICMR, NACO, and other organizations involved in AIDS research should assure that the information is disseminated from NGOs and others involved in behavioural research and intervention development and testing.

9. *Those involved in intervention development and service delivery must contribute to the development of the behavioural research agenda and HIV control policy in India.*

Research priorities should be developed based on the experiences of those involved in trying to effect behavioural change. This is necessary so that research findings are immediately relevant to prevention activities; research priorities reflect the social realities of target populations; and environmental limitations, which restrict behavioural change, are known to researchers. Such information is most available to grassroots organizations. Their knowledge must also be incorporated in political decision-making to assure that effective program decisions are made. One purpose of the workshop was to convey research priority advice from the grassroots to the policy makers and academic researchers.

10. *Those involved in behavioural research and intervention development must be aggressively involved in publicly confronting social and political constraints which limit behavioural research in India.*

Because research on sexuality, injecting drug use, blood donation and use, and other HIV transmission risk behaviours address highly sensitive areas of Indian society, special efforts are required to convince decision makers and the public of the need for and the value of this research. This means that behavioural researchers (in NGOs and other organizations) must be more aggressively involved in public advocacy than are researchers in less controversial areas of health research. The public advocacy must specifically address religious, political, gender and class constraints which limit research essential to control HIV transmission.

11. *Strengthening research and intervention skills*

In order to strengthen the scientific research skills of interventionists and intervention skills of researchers, the following resources are required:

- people power through training by conducting workshops, technical assistance and capacity building, identification of “right” people, constant monitoring and evaluation, standardize information, value clarification;
- building capacity and infrastructure in terms of physical space, people, team-building, computerization through networking and funds.
- advocacy and public awareness through media involvement, systematic documentation, legislations, physicians, para-medical and traditional healers, and health service delivery;
- funding through donor networks and advocacy.

I

Prioritising researchable issues*

1. *Promoting Safer Sex Among Youth*

Youth refers to two age groups: 10 to 14 years and 15 to 19 years as their needs varied. It was crucial to know the contexts of young people's sexual patterns, their attitude/knowledge about safe sex before and in the context of HIV/AIDS. Priority research areas for advocacy and for intervention development were as follows:

- Data on teenage sexual behaviour, STDs, abortions, pregnancies, etc;
- Assessment of how different social institutions like the family, school, media, etc. influence young people's sexuality, sex behaviour and values;
- Perceptions about sexuality;
- Dynamic value systems;
- Enabling and deterrent factors to understanding of sexual and HIV health information and effective means for the same;
- Environmental factors influencing behaviours like family structure, socio-economic conditions, peer group behaviours;
- Correlation between economic power and safe health practices.

Non-government organizations, the Tata Institute of Social Sciences, the Family Planning Association of India, International Institute of Population Studies, National Institute of Public Cooperation and Child Development, USAID, UNICEF, WHO, NACO, Ford Foundation and so on could make resources available for the proposed researches. The additional resources required were funding, technical assistance, training for capacity and infrastructure building and technology transfer.

2. *Promoting Safer Sexual Behaviour Among Adults*

Research priorities for the said group would essentially comprise, firstly, patterns and determinants of sexual behaviour and secondly, approaches to behaviour change. In the former, emphasis needs to be on types of sexual relationships, number of partners, condom use, negotiation skills and alcohol use. It is also crucial to look at life course

* Presentations based on small group discussions.

approach networks, for example, truckers and sex workers and structural or environmental determinants of groups like rural and urban communities, occupational groups and street children, STD and HIV positive patients. Approaches to behaviour change would include the use of existing service delivery models for condom promotion, for example, family welfare or family planning schemes; use of private sector; issues related to counselling and testing; working with men who have sex with men, working with other vulnerable groups like street children, women, etc. and above all, lifting the environmental/structural constraints.

Evaluation needs to be an ongoing process conducted by the implementing agency or by an external research group. There needs to be efforts directed to forging partnerships and in implementing and evaluating data. There was lack of evaluation at present or not enough documented evidence of the same. It was also important for funders to see research and interventions together and to merge the two so as to make them more meaningful.

Rural populations were also at risk as there was concrete evidence to show that the STD rate was higher in the rural areas. It was necessary to look at immediate feeder rural areas surrounding fast growing cities given the high rate of seasonal migration. A recent study undertaken on HIV prevalence in ten districts of Tamil Nadu showed that HIV infection was as much as in the urban areas but more importantly it was as high among low risk populations as the high risk population.

3. *Reproductive Health and Prevention of STD*

Reproductive health research should focus on both women and men. For the purpose of discussion, the definition was limited to events related to reproductive tract infections (RTIs) and STDs.

The research questions identified were:

- Vocabulary relating to people's concerns about RTI/STD and sexual which include explanation/belief systems of causation and cure;
- Health-seeking behaviour;
- Burden of disease (STD/RTI+ complications) in women and men;
- Role of migration, tourism, and religious congregations;
- Belief systems and sources of information of alternate providers of sexual health, attitudes of medical students/allopathic health care providers;
- Male and female barrier methods;
- Safety and efficacy of intervention/prevention technologies;
- Patterns and extent of communication between sexual partners.
- Gender politics and negotiations in sexual relations, choosing parenthood and working towards greater mutuality in heterosexual relations.

The resources available for undertaking the said kind of studies are many because of a growing interest in reproductive health and women's health from various quarters.

I

Prioritising researchable issues^{*}

1. *Promoting Safer Sex Among Youth*

Youth refers to two age groups: 10 to 14 years and 15 to 19 years as their needs varied. It was crucial to know the contexts of young people's sexual patterns, their attitude/knowledge about safe sex before and in the context of HIV/AIDS. Priority research areas for advocacy and for intervention development were as follows:

- Data on teenage sexual behaviour, STDs, abortions, pregnancies, etc;
- Assessment of how different social institutions like the family, school, media, etc. influence young people's sexuality, sex behaviour and values;
- Perceptions about sexuality;
- Dynamic value systems;
- Enabling and deterrent factors to understanding of sexual and HIV health information and effective means for the same;
- Environmental factors influencing behaviours like family structure, socio-economic conditions, peer group behaviours;
- Correlation between economic power and safe health practices.

Non-government organizations, the Tata Institute of Social Sciences, the Family Planning Association of India, International Institute of Population Studies, National Institute of Public Cooperation and Child Development, USAID, UNICEF, WHO, NACO, Ford Foundation and so on could make resources available for the proposed researches. The additional resources required were funding, technical assistance, training for capacity and infrastructure building and technology transfer.

2. *Promoting Safer Sexual Behaviour Among Adults*

Research priorities for the said group would essentially comprise, firstly, patterns and determinants of sexual behaviour and secondly, approaches to behaviour change. In the former, emphasis needs to be on types of sexual relationships, number of partners, condom use, negotiation skills and alcohol use. It is also crucial to look at life course

^{*} Presentations based on small group discussions.

approach networks, for example, truckers and sex workers and structural or environmental determinants of groups like rural and urban communities, occupational groups and street children, STD and HIV positive patients. Approaches to behaviour change would include the use of existing service delivery models for condom promotion, for example, family welfare or family planning schemes; use of private sector; issues related to counselling and testing; working with men who have sex with men, working with other vulnerable groups like street children, women, etc. and above all, lifting the environmental/structural constraints.

Evaluation needs to be an ongoing process conducted by the implementing agency or by an external research group. There needs to be efforts directed to forging partnerships and in implementing and evaluating data. There was lack of evaluation at present or not enough documented evidence of the same. It was also important for funders to see research and interventions together and to merge the two so as to make them more meaningful.

Rural populations were also at risk as there was concrete evidence to show that the STD rate was higher in the rural areas. It was necessary to look at immediate feeder rural areas surrounding fast growing cities given the high rate of seasonal migration. A recent study undertaken on HIV prevalence in ten districts of Tamil Nadu showed that HIV infection was as much as in the urban areas but more importantly it was as high among low risk populations as the high risk population.

3. *Reproductive Health and Prevention of STD*

Reproductive health research should focus on both women and men. For the purpose of discussion, the definition was limited to events related to reproductive tract infections (RTIs) and STDs.

The research questions identified were:

- Vocabulary relating to people's concerns about RTI/STD and sexual which include explanation/belief systems of causation and cure;
- Health-seeking behaviour;
- Burden of disease (STD/RTI+ complications) in women and men;
- Role of migration, tourism, and religious congregations;
- Belief systems and sources of information of alternate providers of sexual health, attitudes of medical students/allopathic health care providers;
- Male and female barrier methods;
- Safety and efficacy of intervention/prevention technologies;
- Patterns and extent of communication between sexual partners.
- Gender politics and negotiations in sexual relations, choosing parenthood and working towards greater mutuality in heterosexual relations.

The resources available for undertaking the said kind of studies are many because of a growing interest in reproductive health and women's health from various quarters.

These include institutes for social sciences, centres for women's studies, departments of preventive and social medicine, non-government and community-based organizations.

4. *Safer Drug Use and Safer Needle Practices to Prevent HIV Transmission*

The themes for research outlined were: what works, where, for whom, under what circumstances, for how long and at what cost, the risk behaviours and risk reduction strategies, interventions centred around making supplies/services available and accessible.

The process would include effective participation of NGOs and researchers and sensitivity while framing research questions to include thick descriptions of the study populations.

The key issues requiring additional research were identified as:

- Extent of injecting behaviour and reasons why people switch from smoking/chasing to injecting;
- Understanding the ritual of injecting and the belief that mixing of blood accentuates the high;
- Difference in behaviour of injecting and non-injecting population;
- Factors that could bring about community acceptance and wipe out the stigma; not using pre-test counselling to "convince" for testing;
- Increase in sexual promiscuity due to the strict vigilance on the border, reduced availability of heroin and phenomenal price increase;
- Efficacy of drug injecting equipment exchange programme;
- Decriminalization impact on risk behaviour in drug use;
- Effectiveness of street-based outreach and outreach to marginalized groups in India;
- Identify and use natural agents of change and gauge their effectiveness in changing risk behaviour; and
- Methods and their effectiveness in preventing secondary infection.

Resources presently available included NGO networks, research personnel and funding agencies. Additional resources required are: access, influence and co-operation of policy makers and funding agencies; information network between organizations and researchers; skill upgradation, regional and international scientific exchanges; and effective and participatory relationships between NGOs and researchers and NGOs, researchers and research participants.

5. *Improving Health Services and Safer Blood Banking in the Indian Context*

Taking Maharashtra as the prototype, the health scenario in the country was presented. The person on whom the whole system rested was the lone "multi-purpose worker" (MPW) who was assigned to every 5,000 population. The assignments of the MPWs include condom distribution, immunization, disinfection of water, control

of diarrhoea, six national programmes for prevention of malaria, filaria, blindness, leprosy, tuberculosis, etc. Their problems in rural areas get aggravated because of the distances they have to cover. For training 8,000 doctors, 16,000 female and male MPWs, the estimated cost would be around 800 million rupees. In lieu of the AIDS epidemic, training has been initiated with the new political decision to focus on cancer, leprosy and AIDS; but the effectivity remains to be questioned.

The key research questions to be explored in the above context include:

- Motivation strategies to mobilize people to utilize STD clinics;
- Exploration of attitudes of the grass-roots workers;
- Introduction of counselling services;
- MPW's capability to cope with additional work load;
- Generation of funds;
- Possibilities of greater intersectoral collaboration amongst social welfare, finance and health departments;
- Integration of other health systems and institutions into mainstream;
- Utilisation of NGOs and academic institutions to assist government;
- Evolving qualitative indicators, a new monitoring system, to ensure working of health system to avoid the target oriented approach;
- Use of research for advocacy;
- Use of bio-safety measures.

Constraints commonly faced in dealing with the system are: constant turnover of AIDS officers; absence of institution building; pre-occupation of economists and hospital administrators to ensure only cost effective programmes; lack of access to information from private institution and quacks.

The resources presently available to the health system are three percent of the total outlay of Rs. 419 crores. NACO provides 2.84 crores for AIDS control. Contribution from the state government is virtually nil. There is an evident lack of political commitment. Regarding blood banking, there were 189 licensed and unlicensed blood banks.

Research priorities in the said sector include:

- Compilation of actual data;
- Blood transfusion systems;
- People's health seeking behaviour especially with respect to blood;
- Professional blood donor practices;
- Appropriate health education for masses and their empowerment to ensure accountability;
- Importance of counselling in blood banks.

UNICEF was concerned about the enormous amount of blood used for treating anaemia and preventing maternal mortality and agreed to emphasize rational blood

use. However, according to a study, only 16 to 20 percent of women who actually need the blood get to hospitals. It was crucial to examine what motivated/demotivated people for voluntary blood donation and also the attitudes of doctors dealing with HIV positive people. Attendance in government STD clinics was low because of stigma. A study revealed that out of 147 AIDS cases, 24 were through blood transfusions and 15 were through one unit transfusion.

It was obvious that AIDS had caused everybody to relook at the existing health delivery systems and paradigms not only in India, but all over the world. It was crucial to reorganize and restructure the system in the context of other programmes. There was need to redesign reproductive health system package in India to be able to tackle the issues around HIV/AIDS.

6. *Social Support and Care*

Social support and care was defined as comprehensive HIV/AIDS care implying medical, nursing, counselling and social support. The elements of social support constituted health care, economic support, legal support, social support by countering discrimination and fostering acceptance, housing, employment and rehabilitation. The need to provide care and support was being increasingly felt by NGOs, health functionaries, researchers, individuals and families especially in the states of Maharashtra, Tamil Nadu, and Manipur for AIDS patients and in Delhi and Pondicherry for HIV positive people.

There was need to plan and review:

- Comprehensive care policies and guidelines including clinical management, nursing care, counselling and social support;
- Resource mobilization across the care continuum including discharge planning and referral networks;
- Integration of HIV/AIDS care with existing services including in and out patient care, health centres and dispensaries;
- Prevention intervention as part of care including counselling partners of people with AIDS (PWAs), supply of condoms, family education, using persons with HIV/AIDS as prevention educators and stimulating support groups among them.

The important research questions that emerged were:

- Strategies to integrate care and support into existing health and social care structures;
- Lessons to be learnt from existing efforts;
- Needs at different levels including hospitals, health care facilities, NGOs, community based organizations and families and individuals;
- Assessment and modification of training program for health care workers to achieve a change in attitudes and provision of better care;
- Quality of counselling;

- Use of appropriate bio-safety measures within the given constraints at various health care facilities;
- Role of alternate systems of medicine;
- The burden and cost of caring on the providers;
- The assumption of family being a safety net in developing countries.

Resources presently available for the above included technical expertise in research institutions, social institutes, some NGOs and some health care providers as well as the World Health Organization, infrastructure for the provision of health care, research experiences at other locations, and availability of training manuals.

Additional resources needed for the purpose included:

- Identification of key institutions for research in care and support;
- Capacity building of institutions and other collaborating researchers/NGOs;
- Strengthening of key institutions to function as resource centres;
- Mechanisms for sharing and dissemination and funding support.

There was now a heightened level of sensitivity in the government after the plague episode. The time was thus ripe for strong advocacy for greater allocation for health, emphasis on preventive care and training of health care workers.

Targetted Interventions

1. The program on sex education should be particularly imparted to both low income and middle income groups, as there is resistance to the use of condoms in the latter group.
2. It was crucial not to view empowerment of women only in the context of HIV/AIDS but there was need to undertake broader community level programs targetted at girls, boys, women and men.
3. It was important to look at reproductive health with respect to different programmatic linkages since there was an inextricable link between providers, service delivery, clients and research. It was also necessary to take a complete relook at technologies which also had these intersections. Some technologies which may be called "safe" for preventing pregnancies may not be safe for infection prevention and vice versa, for example, IUDs. There was need to examine women's perceptions of the problems and causation of reproductive tract infections.
4. There was need to reach out to non-school going population especially in rural areas.
5. There was need to include public health services sector, STD clinics and quacks in prevention programs. While NACO was planning programs to involve the private sector as well as look into issues of mandatory testing, organizations like the Indian Medical Association could be instrumental in raising awareness.

6. Interventions for suicide prevention in HIV positive people also need to be addressed.
7. Follow up was essential after training programs.

II

Research methodologies to study various groups*

Rural women not necessarily perceived to be at risk

The assumptions underlying the research were:

- Rural areas in Bombay-Pune-Nasik belt
- Identified an NGO working mainly in adult literacy
- The NGO, out of concern about women's reproductive health, contacts an institute which agrees to collaborate and conduct a study to plan interventions.

Preliminary steps involved:

- Meeting in the village with the NGO, mahila mandals, multipurpose workers and others.
- Quick round of key informant interviews on existence of risk factors, reproductive health problems, problems of migration, travel, information from multipurpose workers/traditional birth attendants/*dai* and private practitioners on stillbirth, opthalmia in neonatals, information from boys in the street on bars and liquor stores.

Data would be collected by the researcher, the representative from the NGO and trained local field workers. The time frame envisaged for development of a framework, training, data collection, analysis, report writing and sharing to developing interventions was five months. Formative research was sought to be done through key informant interviews, focus group discussions and PRA.

Street kids aged between 8-16 years in Bombay

Indicators/objectives of the study included:

- Increased health seeking for STD treatment
- Reduction in STDs
- Reduced number of sexual contacts
- Reduced number of risky contacts
- Reduction in IDU
- Reduction in unsafe injection practices

* Presentations based on small group discussion.

Resources available were cited as NGOs working with street kids and NGOs with interest and capacity to work with street kids.

The research process was divided into phases. The first phase was envisaged to take about three months comprising:

1. (a) NGOs and researchers agree on details of collaboration, identify primary and secondary data sources as being NGO, staff, street kids, ex-street kids, police, health practitioners and NGO, NACO, UNICEF, WHO reports respectively.
(b) Identification of training needs and divide tasks of data collection.
2. Collection of background data regarding occupation, location, support systems, access and availability of health care, literacy levels, sexual behaviours, drug use and vocabulary.
3. Imparting of training in research techniques to NGO and of the NGO context to researchers.

Phase two was envisaged for a three month period to comprise details of formative research on the above aspects and baseline survey through focus group discussions and key informant interviews.

The third phase, for the next three months, was to comprise training and intervention finalization. The next stage of actual intervention was to be for two years accompanied by ongoing monitoring and evaluation to assess the obstacles to behavioural change after increased awareness and progress of the program.

The fourth phase of evaluation and write up was to be of three months where the process would be examined, baseline survey re-administered, followed by analysis and write-up.

Intravenous Drug Users

The goal of the research was to influence policy makers and demonstrate the workability of certain interventions and provide service. The group outlined the key issues in planning interventions with IDUs as follows:

- Unclear social networks of IDUs
- Availability of smokable forms of opiates
- Non-availability of white heroin; "brown sugar" available but expensive, leading to use of synthetic drugs
- Intra muscular injection through cuts
- 75% sharing of equipment but many clean with water
- Role of alternative health care givers like quacks
- Injection by spouses/friends

According to the group, intervention research with IDU populations would include:

- Background

- Formative research
- Intervention research/design

The time frame envisaged was one year for formative research and one year for intervention. Formative research was envisaged in a step-wise fashion as follows:

1. **Step 1** - Map geographical location of IDUs and dealers through key informants, service providers and police
2. **Step 2** - Use above maps to identify specific target areas for research and map the same intensively
3. **Step 3** - Individual interviews to identify needs of addicts, types of drugs and access, where injecting takes place, risk perception, knowledge of HIV and demographic characteristics. This would also include sexual behaviour, sexual history, beliefs about injection and sequence, health seeking behaviour, etc. Interviews of quacks, spouses and close friends and detailed case studies were also part of this process.

Prior to planning interventions, certain issues had to be contended with and resolved. They included:

- Need for formative research
- Perception of the target population about best approach
- Using ex-addicts
- Outcome indicators including sharing, no IDU, cleaning equipment and sexual risk
- Possible services to be provided and the effect on intervention.

Ideas for intervention were exchange of injection equipment, bleach distribution and work with alternative health providers like quacks, and training to clean equipment.

Rural migrant men

The group began by defining migrant men from census data, economic strata and the particular migrant population to understand the present scenario for AIDS intervention. And finally decided to focus only on seasonal migrants who left their families and spouses behind and moved in a cluster from their villages. Subsequently, the group decided to focus on "sugar factory workers".

Background information on the industry, working conditions, facilities for employees, demographic data, life style patterns, media influences, health seeking behaviour for STDs, high risk behaviour and use of family planning methods, perceptions and attitudes towards health, physical conditions, etc. was sought to be collected through the personnel in the sugar factory, surrounding rural area, primary health centre, key informants and the migrants themselves. The data was to be collected through focus group discussions, indepth interviews and other secondary sources and key informant interviews. There was a need to understand behaviour of the men, both in the place

of work and back home, in different cultural contexts with different pressures, and to examine the existing STD services to strengthen the same after gauging knowledge/awareness and attitudes.

Interventions with built-in evaluations was sought to be initiated at one factory in Maharashtra with 400-500 employees. The focus was to be on advocacy with authorities in the factory. Entry points were envisaged as leisure sites, living quarters and intervention by provision of recreational/sports facilities, etc. Main issues for discussion were to be information on AIDS, availability of condoms and men who have sex with men (MSM) through audio-visual material, group discussions, etc. Other interventions were to include CSWs, health providers and management and enlist participation of other NGOs in the area.

Men who have sex with men

The first issue was the identification of the target population because the “gay identified” group was pretty small. The other groups were MSM who were married or were to be married, male CSWs including seasonal workers, massage boys and hotel employees and situational MSM as in jails or boarding houses. Geographical identification were spots for migratory men in industrial or agricultural sector, public sex environments like beaches, bars, trains, parks or public toilets.

The other issue was the contribution of this segment to the AIDS epidemic since the total population was unknown. The risk behaviour included anal penetrative sex, mutual masturbation and risk to heterosexual populations as well.

The desired goals of interventions were:

- Increase in condom use with anal/vaginal sex
- Increased STD treatment and referral
- Decrease in penetrative versus other sex acts

Formative research for intervention development would include basic demographic information, risk practices, context of sex, condom use and availability, perceived risk, history of STD, health seeking behaviour and police/political harassment. Preliminary information could also be sought from hospital/STD clinic data, key informants, 65-city study, private practitioners, politicians and police. Subsequently perceptions of the needs of target group would also be gauged on the appropriateness of intervention, feedback on potential interventions and important concerns in life.

Based on the data obtained through the above process, it would become crucial to develop an intervention plan which focussed on identification and training of peer leaders, networking support systems, “drop-in” centres, STD referral cards, non-discrimination and anonymous evaluation, condom handouts in parts by outreach workers, and peer leaders.

The group also dwelt a little on the possibility to identify cohorts for the study or adopt a multiple cross sectional sample combination. Methods of data collection would

include interviews, self administered questionnaires and secondary data like self-reports and STD cards.

There was discussion whether the said group was at all a high risk group in India and the difficulty in accessing the group. There was concern expressed over gaining access by intimating park maintainers, politicians, police, bar owners, etc. and exposing these people to a lot of danger and risk. Usually, people like park maintainers were sympathetic to MSM and that efforts were on to arrange for drop-in centres where such activities could be carried out so that the people are not victimized for "objectionable behaviour".

III

Workshop Agenda

Day 1 : Monday — April 24, 1995

9:00 — 9:30 a.m.

Registration

9:30 — 10:00 a.m.

Welcome : *V. Nadkarni*

Inauguration

10:00 — 10:30 a.m.

Introduction to Workshop Objectives :
V. Nadkarni & Gray Handley

10:30 — 10:45 a.m.

Vote of Thanks : *J. Van Dam*

10:45 — 11:15 a.m.

Tea Break

11:15 a.m. — 12: 15 p.m

Chairperson : *Micheal Sweat*
Plenary Session I: Review of Behavioural
Research Needs and Challenges Related to
the Global Prevention of HIV/AIDS

11:15 a.m — 11:45 a.m.

Presentation: *Peter Aggleton & Kevin O'Reilly.*

11:45 a.m — 12:15 p.m.

Discussion

12:15 — 1:30 p.m.

Chairperson : *M.R. Jagtap*
Plenary Session II: The HIV/AIDS Epidemic
and Patterns of Risk Behaviour in India

12:15 — 12:45 p.m.

Epidemiological Features of the
Transmission of HIV and Other STDs
in India : *P.Salil*

12:45 — 1:30 p.m.

Discussion

1:30 — 2:30 p.m.

Lunch Break

2:30 — 4:45 p.m.	Chairperson : <i>Micheal Koenig</i> Plenary Session II (Continued)
2:30 — 2:50 p.m.	Overview of Research on Sexual and other Risk-Related Behaviour and Interventions in India. Analysis of Trends: <i>V. Nadkarni</i> Overview on Research on Sexual Behaviour and Drugs. : <i>Moni Nag</i> Presentation of "65-City Study on High-Risk Behaviour in India": <i>Geeta Sethi</i>
3:30 — 3:45 p.m.	Tea Break
3:45 — 5:00 p.m.	Discussion

Day 2 : Tuesday — April 25, 1995

9:00a.m. — 1:00 p.m.	Plenary Session III: Identification of Potential Areas for Enhanced Behavioral Research in India. Presentation and discussion of Field Reports from Practitioners involved in HIV/AIDS Intervention Programs and Research.
9:00 — 9:20 a.m.	Chairperson : <i>Rekha Masilamani</i> Focus on Women : <i>V. Chitale</i>
9:20 — 9:50 a.m.	Discussion
9:50 — 10:15 a.m.	Chairperson : <i>Kusum Sehgal</i> Focus on Truck Drivers : <i>Kiran Verma</i>
10:15 — 10:45 a.m.	Discussion
10:45 — 11:00 a.m.	Tea Break
11:00 — 11:30 a.m.	Chairperson : <i>Neeta Mawar</i> Focus on Injecting Drug Users : <i>Eldred Tellis</i>
11:30 a.m. — 12:00 p.m.	Discussion
12:00 — 12:30 p.m.	Chairperson : <i>M. Watsa</i> Focus on Youth : <i>Suniti Solomon</i>
12:30 — 1:00 p.m.	Discussion
1:00 — 1:30 p.m.	Working Groups Briefing
1:30 — 2:30 p.m.	Lunch Break

2:30 — 5:00 p.m.

Working Groups: To Identify Behavioural & Intervention Research Needs in India.

5:00 — 5:30 p.m.

Meeting of Planning Committee

7:00 p.m.

Cultural Evening & Dinner

Day 3 : Wednesday — April 26, 1995

9:00 — 11:00 a.m.

Chairperson : *Saroj Pachauri*
Working Group Presentations

11:00 — 11:15 a.m.

Tea Break

11:15 — 12:00 noon

Discussion

12:00 — 1:30 p.m.

Plenary Session IV: Behavioural/Intervention
Research Design Methodologies :
Field Reports from Other Behavioural
Research Experiences

12:00 — 12:30 p.m.

Chairperson : *Peter Aggleton*

12:30 — 1:30 p.m.

Focus on Women : *B. Setiadi*

1:30 — 2:30 p.m.

Discussion

2:30 — 2:50 p.m.

Lunch Break

2:50 — 3:15 p.m.

Chairperson : *Moni Nag*
Sexual Behaviour Change in the Thai
Military : *Michael Sweat*

3:15 — 3:30 p.m.

Discussion

3:30 — 3:50 p.m.

Tea Break

3:50 — 4:10 p.m.

"Hard-to-Reach" Groups : *Clyde McCoy*

4:15 — 5:15 p.m.

Discussion

5:15 — 5:30 p.m.

Principles for designing behaviour and
Intervention research : *Kevin O'Reilly*

Evening :

Discussion

Meeting of Planning Committee

Day 4 : Thursday - April 27, 1995

9:00 — 9:15 a.m.	Methodological issues in Sexual Behaviour Research Facilitator : <i>D. P Basu</i>
9:15 — 9:45 a.m.	Qualitative Methodologies Facilitator : <i>Pertti Peltö</i>
9:45 — 10:30 a.m.	Discussion
10:30 — 10:45 a.m.	Tea Break
10:45 — 11:30 a.m.	Chairperson : <i>Micheal Koenig</i> Plenary Session V - Round table on Issues Related to Behavioural Research (Principles designing research, ethical issues, and related issues for grants & collaboration) : <i>Peter Aggleton, Geeta Sethi and Gray Handley</i>
11:30 a.m — 1:30 p.m.	Working Group Discussion on development of research programmes.
1:30 — 2:30 p.m.	Lunch
2:30 — 5:00 p.m.	Working Groups (continued)
Evening :	Meeting of Planning Committee

Day 5 : Friday - April 28, 1995

9:00 — 12:00 a.m.	Chairperson : <i>M. Bentley</i> Presentation by Working Groups and discussion.
12:00 — 12:30 a.m.	Summary of workshop results and future directions : <i>Isabelle De Zoysa</i>
12:30 — 1:30 a.m.	Valedictory address : <i>S.Y. Qureshi</i> Concluding remarks : <i>Gray Handley</i> Vote of thanks : <i>Shankar Das</i>
1:30 — 2:30 p.m.	Lunch
Afternoon :	Possible Individual Consultations and Project Preparation.

IV

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RESULTS OF THE INDO-U.S. WORKSHOP ON BEHAVIORAL RESEARCH FOR THE PREVENTION OF HIV IN INDIA

As a result of the Workshop on Behavioural Research for the prevention of HIV in India, a number of actions have occurred. Twelve collaborative behavioural research projects are under development and will be submitted for consideration for U.S.-India Rupee fund support.

Four Indian investigators have been supported for training and scientific conference attendance in the United States. Two workshops have been held on behavioural research and injecting drug abuse, one in New Delhi with national attendance and one in Imphal, Manipur, with attenders from the North-eastern states. An additional workshop on HIV vaccines is being planned for 1996.

Ten U.S. investigators have visited potential collaborators in India to develop joint research projects. An NIH dollar award has been made for behavioural research on truck drivers in Punjab and the World AIDS Foundation is considering additional proposals.

In addition to these tangible benefits, there continue to be numerous important scientist-to-scientist contacts which facilitate the transfer of technology between India and the U.S. and the improvement of each country's efforts to control the transmission of HIV.

This report is dedicated to all those who have supported and participated in making this workshop a success.

This workshop has led to new collaborative relationships between Indian and U.S. based researchers. We hope that these will continue and flourish.

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